Supplemental Material for: A Review of Advocate/Scientist Collaboration in Federal Environmental Breast Cancer Research

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Recommendations

Based on our findings, we provide the following recommendations for organizations that require community or advocate participatory components within their RFAs and project PIs on such participatory research projects. More specifically, these recommendations seek to improve the advocate/scientist collaboration in the next NIEHS and NCI breast cancer and environment research project, due to start this year. These recommendations would improve the collaborative process by addressing underlying norms and assumptions at the initial stages of the collaboration, increasing clarity and trust among all participants and thereby reducing frustration.

Commitment to a Participatory Research Approach

For future breast cancer and environment research projects or other similar projects, there needs to be a clear and informed commitment from all participants, both advocate and

scientist, to a participatory research approach as an alternative inquiry paradigm. Although the RFA for the BCERCs stipulated advocate involvement, advocates and scientists brought into the projects by the principal investigators did not necessarily have previous experience with participatory research, understand the principles of participatory research, or commit to a fully collaborative research process. Principal investigators brought scientists in based on relevant research expertise. While this may work for research projects based on a positivist model of scientific inquiry, it is not sufficient for a CBPR approach to scientific inquiry. Scientists can still be brought in based on their scientific expertise, but they need to also commit to a participatory approach. Similarly, advocates that participated without prior experience or training in participatory research were much more hesitant and unclear about what their role could or should be in the collaborative research process than advocates with a prior commitment to and practice in CBPR. In future projects, all participants must be informed about and explicitly commit to a participatory research approach.

Participatory Research Training for Advocates and Scientists

Our interview findings suggested that many advocates and scientists joined the BCERCs without knowing anything about participatory research. Because many scientists and advocates do not have previous experience with participatory research, an initial stage of the research process should include participatory research training. This might include separate training for advocates and scientists. The training for advocates could be led by an advocate who has experience with participatory research and the training for scientists could be conducted by a scientist with previous participatory research experience. The training would introduce all participants to a participatory research process. It would cover the potential benefits and challenges of utilizing such an approach. The advocate training would cover

relevant basic science training, past advocate participation in these types of projects, and a discussion about advocates' desired role in the current project. The scientist training would cover the roles that advocates have played in past participatory research projects and a discussion of the role that they could play in the specific project at hand. It might be beneficial to have this type of training before including particular organizations or scientists on a project application. The training would allow advocates and researchers to decide if this is something that they want to participate in. If an advocate feels that he or she does not feel comfortable participating for any reason or if a scientist realizes that he or she prefers to work on individually on research projects without input from advocates, s/he could then decide not to participate. Ideally, funders of participatory research projects would fund the initial training program. At that point, it could be up to the PI at individual centers to coordinate the training utilizing advocates and scientists who are experienced with participatory research to lead the trainings.

Based on our interviews, it was clear that commitment to and understanding of participatory research varied between Centers as well as among advocates and scientists within Centers. The full benefits of participatory research are compromised when all participants do not have relevant training. Scientists who have previously only worked within a positivist scientific inquiry paradigm often become frustrated with the "slowing down" of the scientific process that comes along with engages advocates in research. At the same time, advocates who are being brought into participatory projects for the first time are often hesitant about what their role should be and intimidated by scientists, therefore they may not fully participate. Advocate and scientist training in participatory research would introduce scientists to this alternative inquiry paradigm, adjusting their expectations about how the scientific

process would work in these projects and thereby reducing frustration. It would also bring advocates into the fold, familiarizing them with scientific processes, and specifically about the important role that they must play in participatory research.

To reduce communication problems which often lead to frustration among advocates and scientists, training should not only address the principles of CBPR, but also train advocates in relevant epidemiology and basic science as well as train scientists to communicate complex scientific information clearly to advocates. As we discovered through our interviews with advocates from the Bay Area BCERC and a scientist from the MSU BCERC, there are certain "experienced advocates" and "advocate scientists" who are ideally positioned to facilitate this process. "Experienced advocates" have previous experience with CBPR and are knowledgeable about the relevant science. "Advocate scientists" are scientists who also view themselves as advocates with a commitment not only to scientific research, but also to preventing breast cancer. Given their positions at the nexus of advocacy and scientific expertise, these experienced advocates and advocate scientists can lead the way in developing participatory research training for advocates and scientists who are new to the approach.

Clear Definition of Advocates' Role in Research

In addition to general training in CBPR, advocates and scientists need to agree upon and clearly delineate their respective roles in the research. While CBPR calls for full collaboration between advocates and scientists, the actual practice is often hampered by a lack of clarity about the roles that advocates should play in the research process. In the BCERCs, advocates who lacked training and experience in participatory research were often somewhat removed from the research process, attending meetings where scientists updated them on the status of the research and waiting for some results to come out of the study for them to report to their

communities. When advocates were not particularly involved in the BCERC, scientists also became confused as to what the purpose of the advocates' involvement was beyond securing funding for scientific research on breast cancer and the environment, which scientists often acknowledged and appreciated. However, in the Bay Area BCERC where advocates were more familiar with CBPR, they were more able to negotiate their role in the project. This led to more shared ownership of the research process as well as research outcomes between advocates and scientists, which is a core principle of CBPR (Israel et al. 1998).

Clearly Defined Decision-Making Process

Related to clearly defining advocates' roles in the research process, future collaboration also requires a clearly defined decision-making process. Participatory research requires collaborative decision-making regarding research priorities, division of tasks, allocation of funds within each Center, and forms of advocate and scientist participation. A number of both advocates and scientists expressed frustration regarding how decisions were made. Scientists who had previously worked alone or only with other scientists were not accustomed to the level of deliberation required by a participatory approach. The attitudes of scientists were particularly important given that the COTCs were under-resourced and structurally disempowered. Without a clearly defined decision-making process, advocates were often unclear about how to make sure their views were taken into account. Scientists' attitudes would be less important, or at least mitigated, if they could be held accountable and required to negotiate with COTCs instead of having the option to ignore them. For the development of the BCERP and other similar projects, much frustration as well as concerns over trust and respect can be reduced if an agreed-upon decision-making process is followed throughout the collaboration.

Deliberation and Agreement on Allocation of Funds

Finally, in order for advocates to be truly incorporated into the research process on an equal level, there must be deliberation and agreement on the allocation of BCERC funds. The funding allocated for translation and dissemination of research findings is very limited. The current round of BCERC funding budgeted 5% of the total grant for the Community-based Outreach and Translation Core. In the Bay Area BCERC, which, as previously stated, consists of a number of advocates with CBPR experience, the COTC members negotiated further funding for their COTC out of the epidemiology and molecular biology budgets. As one Bay Area BCERC advocate stated regarding why they requested additional funds from the other parts of the Center, "we believed in this community-based participatory research approach, and believed that input from non-scientists was as valuable as the input from researchers, as a sign of the two projects." Based on a CBPR approach, all participants, after having training in the approach and committing to it should they participate in similar projects in the future, would negotiate the allocation of the funding with true collaboration and community-relevant outcomes in mind.

These recommendations are based on past research regarding effective CBPR, as well as the underlying challenges we have found in the BCERCs, some of which fall outside of structural guidelines in much CBPR analysis. The adoption of these recommendations in future breast cancer and environment community-based research projects or other CBPR projects can help alleviate—potentially avoid altogether—many of the controversies that such collaborations have faced.

Supplemental Table 1. Breast Cancer and Environment Research Centers' COTC Affiliated Organizations and Their Focus Areas

University of California, San Francisco	**University of Cincinnati**	**Fox Chase Cancer Center**	**Michigan State University**
Zero Breast Cancer*—finding the causes of breast cancer through community participation in the research process http://www.zerobreastcancer.org/	Breast Cancer Alliance of Greater Cincinnati*—breast cancer advocacy, education, and communication http://www.bcacincy.org/	The Renaissance University for Community Education of the Harlem Children's Zone Project*—strengthening families, providing opportunities for sustainable social and economic well-being, and creating physical environments that foster learning and growth http://ncfy.acf.hhs.gov/publications/guide/fnc.htm	Cancer Prevention & Control Section of the Michigan Department of Community Health—protecting and improving the health of MI's citizens www.mich.gov/mdch
Bayview Hunters Point Health & Environmental Assessment Task Force*—teaching residents about environmental factors influencing their health in a group setting.	National Breast Cancer Coalition*—lobbying at the national, state and local levels for public policies that impact breast cancer research, diagnosis and treatment http://www.stopbreastcancer.org/	Girls, Inc.*—specializes in services for girls, young women, and their families with particular emphasis on those in at-risk situations www.girlsinc.org	Faith Access to Community Economic Development— providing services to meet the physical, mental, and spiritual health needs of low-income residents of Flint/Genesee County
Bay Area Breast Cancer SPORE*—improving diagnosis, prognostication, and therapy of breast cancer	Pink Ribbon Girls*—breast cancer education and awareness for early detection, support and an providing an outlet to express fears http://www.pinkribbongirls.org/	New York City Parks Foundation—community-building through park initiatives including free arts, sports, and education programs http://cityparksfoundation.org/	Susan G. Komen Breast Cancer Foundation— spreading the message of early detection and financially supporting breast cancer screening, education, treatment and support programs in Clinton, Eaton and Ingham counties http://www.komenmidmichigan.org/

Supplemental Table 1 (cont.)

University of California, San Francisco	**University of Cincinnati**	**Fox Chase Cancer Center**	**Michigan State University**
Breast Cancer Fund—advocating for elimination of the environmental and other preventable causes of breast cancer http://www.breastcancerfund.org/	Patterns Inc.—No information available	Share—serving a regional network of community organizations engaged in food distribution, education, and advocacy	Michigan Environmental Council— promoting public policies supporting clear waters, clean beaches, beautiful landscapes and healthy communities http://www.environmentalcouncil.org/
Alameda County Public Health Department*—working to improve the health and safety of its residents and the neighborhoods they live in http://www.acphd.org/	Sisters Network Cincinnati*—committed to increasing attention to the impact of breast cancer on the African American community http://www.sistersnetworkcincy.org/		American Cancer Society, Great Lakes Division— preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service www.cancer.org
Marin County Department of Public Health*— promoting and protecting the health, well being, self-sufficiency and safety of all people in Marin County	Greater Cincinnati Occupational Health Center—specializes in emergency response and hazardous worker operations http://www.gcohc.com/		
	Susan G. Komen Breast Cancer Foundation,Greater Cincinnati Affiliate—fundraising to raise funds for breast cancer research and ultimately curing breast cancer http://www.komencincinnati.org/		

Supplemental Table 1 (cont.)

University of California, San Francisco	University of Cincinnati	Fox Chase Cancer Center	Michigan State University
	YWCA Breast & Cervical Health Network—ensuring that underserved women in Cincinnati are educated, screened, and supported for breast and cervical cancer http://www.ywca.org/site/pp.asp?c=agLGKXNOE&b=263720		
	The Wellness Community—cancer support group http://www.thewellnesscommunity.org/		
	American Cancer Society, Cincinnati Area Office—preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service www.cancer.org		
	Breast and Cervical Cancer Screening Project—providing screening services and health care coverage to eligible women		

Information about the organizations' focus areas was obtained through their websites [accessed 4 June 2010]
*Indicates that the organization has a representative in the COTC leadership of the Center